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The AIDS Project

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THE AIDS PROJECT NEWS

P.O. BOX 10723

OCTOBER, 1986

PORTLAND, ME 04104

AZT: A BREAKTHROUGH

(The following is excerpted from AIDS ACTION UPDATE #6 put out by the AIDS ACTION COUNCIL, 729 Eighth St., S.E., Wash., D.C., 20003. The AAC was involved in lobbying that led to the quickness of both the legislative and Public Health Service response to bring about this milestone in AIDS research and treatment. The AIDS Project lauds their efforts, and all the many others, involved in this breakthrough.)

On Sept. 19, the Public Health Service and the Burroughs Wellcome Company held a press conference to announce initial research evidence which suggests that azidothymidine (or AZT, or Compound S) appears to inhibit the method by which the HIV virus copies its genetic material onto host cells. Phase I and Phase II trials of the drug in a limited number of patients had produced clear clinical improvement, an enhanced sense of well-being and prolongation of life in a majority of those study participants receiving it.

Officials cautioned that AZT is not a miracle drug or a cure. It has caused some negative side effects, and much remains to be learned about its long-term efficacy.

The Public Health Service has set up a national AZT hotline, operating seven days a week from 8 a.m. to 12 midnight Eastern Daylight Time, for inquiries from physicians and Persons with AIDS who are interested in treatment referral. That number is 1-800-843-9388.

AZT may only be prescribed by physicians through registered hospital pharmacies in any given location. Therefore physicians must formally request registration packets by calling the AZT hotline number.

A separate packet of basic information and an informed consent form is also available to eligible People with AIDS.

Persons eligible for AZT protocols at this time are those who:

- * can document one or more bouts with PCP;
- * are not now receiving any other drug therapy for AIDS;
- * are not receiving chemotherapy of other drugs that are toxic to the kidneys or bone marrow;
- * have adequate liver and kidney function as well as sufficiently high red and white blood cell counts;
- * and are not children, pregnant women or nursing mothers.

Criteria for patient inclusion are limited because the drug has only been shown to be effective in studies involving those Persons with AIDS outlined above.

Phase I trials showed clearly that a majority of patients enrolled had increases in their circulating helper T-cells. Six of 19 patients with inactive immune responses developed positive skin tests and one patient had restoration of a virus-specific cytotoxic T-cell response. In addition, two patients had clearing of chronic fungal infections (a common condition in AIDS), 13 patients had weight gains of four pounds or more and six others had other signs of clinical improvement.

Phase II trials proved conclusively that patients receiving AZT lived longer than those receiving a placebo. To date, 16 of 137 placebo recipients have died, while 1 of 145 patients receiving AZT did. Those receiving AZT also had a decreased number of "significant medical events" including opportunistic infections. Phase II trials confirmed the weight gains and improved daily functioning that Phase I trials had already shown.

In both sets of trials, AZT was also shown to cross the blood/brain barrier--a finding that has potential significance for AIDS-related neurological complications although no efficacy has yet been proven in this regard.

Some patients in both trials experienced nausea and mild, intermittent headaches. A number of patients had a reversible decrease in their ability to form new red and white blood cells (i.e. mild bone marrow suppression). In some patients, new red blood cell formation was inhibited to the extent that transfusions were required. Red blood cell production resumed, however, when dosages were modified. There has been no evidence of kidney, liver or cardiac dysfunction attributed to AZT.

It should also be pointed out that, although preliminary data indicate that AZT reduces mortality in some Persons with AIDS and ARC, it's not known yet how long patients may be able to tolerate the drug, how long the positive responses can be sustained or whether modifications in dosage can eliminate some or all of the side effects.

At a conference in Boston at Mass General Hospital on Sept. 26, Dr. Martin S. Hirsch, (Associate Professor of Medicine, Harvard Medical School; Associate Physician, MGH) gave some optimistic information about AZT. Benefits of the drug include its ability to get into the brain, that it can be taken in oral form, that it does inhibit viral replication, and that it does not appear to be "inhibitive of immune functions". He gave figures for the mortality rates among the placebo and AZT cohorts: of the 16 patients who died who were receiving placebos, 11 were People with AIDS, 5 were People with ARC; the 1 person who died from the group receiving AZT was a Person with AIDS. In those receiving AZT there was a 50% reduction in the onset of opportunistic infections.

On the cautionary side, Dr. Hirsch stated that "the only population this drug has effect upon is those who have had PCP, and possibly those with advanced ARC". He said it would be "most unwise" for healthy seropositive people to take AZT due to the destruction of Red Blood Cells and the resulting need for transfusions. "I don't know if the drug will benefit" (seropositives) "or if toxicity will make them worse."

Another cautionary statement Dr. Hirsch made was to note that the drug manufacturer will make AZT available for free to people who qualify for it right now, but come the first of the year patients will have to pay for the drug. "It won't be cheap", he said. His estimated cost per patient for a year's course of treatment on the drug was \$8000

AIDS SUMMIT YIELDS COALITION by R.J. Bass

At the Second Annual AIDS Summit for the Gay and Lesbian Community held on Sept. 14, it was decided to form the Coalition of AIDS Service Providers. This coalition will initially be comprised of grass-roots organizations that are providing some type of AIDS-related direct service. These services include education, training, support groups, referrals, hotlines, counseling, etc.

There are several reasons for organizing the coalition:

1. To ease communication among various groups working with AIDS;
2. To present a united front when dealing with funding, politics, etc., and to lessen the likelihood of competition for limited funding.
3. To address AIDS-related issues on a statewide basis.
4. To formalize and streamline our current ad hoc process of communicating and programming.

A first meeting has been planned for late in October. For more information on the Coalition and the 1st meeting, call R.J. Bass at 207-236-9593.

LEWISTON GROUP CHANGES NAME, LEADERSHIP by Gary L. Anderson

Recent changes have occurred in the Lewiston based Central Maine Health Foundation. The group has changed its name to AIDS Action of Central Maine and Al Hurley is the new President of the Board of Directors. AACM is reorganizing its whole operations to be more responsive to Lewiston and Central Maine's needs. The Lewiston Hotline will be upgraded and more efforts to provide education to the at-risk communities and the public at large will occur. Already slated is a joint educational effort with the Gay Lesbian Straight Alliance of Bates College (see Calendar). For more information, contact Al Hurley at 782-6615.

MAINE ART AUCTION TO BENEFIT AIDS IN NOVEMBER

Visual Aid is an art auction whose purpose is to raise money for AIDS research and assist AIDS patients in Maine. A preview and inspection will be held Friday, November 21, 1986 and the auction will be held Saturday night, November 22, 1986 at One City Center in Portland, Maine.

Featured are works by prominent Maine artists as well as artists who reside elsewhere but maintain connections with the State of Maine. Media will include oil paintings, watercolors, mixed colors, mixed media, silkscreen prints, sculpture, jewelry, furniture, and one of a kind clothing.

For further information, write VISUAL AID, P.O. Box 4340, Sta. A, Portland, ME 04101-4340. Or call 207-623-5274. Financial donations accepted.

A Legislative Joint Select Committee to Study Insurance Pools for High Risk Groups has been meeting over the summer to develop a plan for a high risk insurance pool for Maine. The specifications are:

1. Maximum lifetime benefit of \$500,000;
2. Deductibles: \$500 min.--\$1000 max., 20% of bills paid by the insured person after deductible--up to the out-of-pocket expenses limit;
3. Max. out-of-pocket expense: \$1,500 individual, \$3000 family;
4. Premium: not to exceed 150% of standard individual rate for the defined benefit package;
5. Waiting period for pre-existing condition: 6 months for conditions treated within a 6 month period prior to application. Waiting period will be waived if one had insurance through employer and lost it voluntarily or involuntarily. Waiting period can be bought out if the individual desires. A \$1000 worth of benefits will be paid for the pre-existing condition during the 6 month waiting period to maintain the condition.
6. Eligibility: Must have been rejected by one insurance carrier or be unable to get coverage at an equal rate or be unable to get coverage only with a lengthy rider.
7. Benefits: Mandated benefits plus benefits in standard group plan, including alternative care. Managed care required.
8. Cost: Insurance pool will either be funded through the State General Fund or by a tax on insurance companies.

I have lobbied to have the pool reflect the needs of Persons with AIDS (PWAs). My efforts centered on #5. I managed to get a buy-out of the waiting period and a \$1000 maintenance of a pre-existing condition included.

A bill will be proposed by the Select Committee in the next session of the Legislature. The bill has a much better chance of passing if it is funded by an assessment on the insurance companies rather than by the General Fund. Please lobby the legislators on the committee about the method of funding: Rep. Merle Nelson, Rep. Peter Manning, Sen. Barbara Gill, and Sen Charlotte Sewall.

HTLV-3 ANTIBODY COUNSELING

Voluntary — Anonymous — Confidential — Free — Days or Evenings

The AIDS Project now provides trained counselors to answer your questions and address your concerns about possible exposure to the AIDS virus. **To schedule a counseling session call: 774-6877**

For more information call:

AIDS-LINE

1-800-851-AIDS

**THE
AIDS
PROJECT**

visual aid AN ART AUCTION

P.O. Box 4340, Station A, Portland, ME 04101
(207) 623-5274

I would like to support VISUAL AID as a:

_____ Patron, \$250 or more

_____ Benefactor, \$100 to \$250

_____ Sponsor, \$50 to \$100

_____ Friend \$20 to \$50

_____ Other - Amount _____

Name: _____

Address: _____

ADVISORY COMMITTEE MEETS

On September 2, the first meeting of the **Committee to Advise the Commission of the Department of Human Services on AIDS** met in Augusta. Presentations were made to the committee by Bureau of Health personnel and Gary Anderson, Executive Director of The AIDS Project. Committee members viewed a videotape on AIDS developed for staff working in correctional facilities as an example of the types of specific instructional materials that are available to teach people about AIDS. It was decided to break the committee into three sub-committees to better tackle the many issues facing the group. A list of the initial topics for the sub-committees follows:

PATIENT CARE FOR PERSONS WITH AIDS AND ARC, to include Medicaid/Medicare issues, hospital and hospice care, home care and family member concerns.

EDUCATION, to include employer/employee issues, risk groups, health professionals, school boards, and the general public.

COUNSELING AND TESTING, to include concerns with confidentiality, HIV testing groups, insurance, civil rights regarding testing, reporting problems, and blood protection.

Committee to Advise the Commissioner of the Department of Human Services on AIDS

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Bath, ME 04530

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Representing

Funeral Directors

Maine Hospice Council

Supt. of Schools, Union No. 52

Maine Dental Association

Maine Osteopathic Association
Oncologist

Infectious Disease Specialist

Human Rights Commission
State House Station 51

Maine Health Care Association
(Nursing Home)

Maine Psychological Association
317 Water Street, PO Box 2427

Council #93, AFSCME, AFL-CIO

ME Lesbian/Gay Political Alliance

Director, AIDS Project Inc.

Blue Cross/Blue Shield

Substance Abuse

Sub Committee

Patient Care

Education

Patient Care

Patient Care
Counselling and Testing

Patient Care
Education

Education

Education

Counselling and Testing

Counselling and Testing

Education, Coordinator

Patient Care

Patient Care

Counselling and Testing

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Tel: 289-1505
773-4984

Philip W. Haines, Dr. P.H.,
Acting Director
Bureau of Health
State House Station 11
Augusta, ME 04333
Tel: 289-3201

Chair of Committee
State Representative

National Association of
Social Workers

Maine Teachers Association

Eastern Maine Medical Center

Maine Public Health Assoc.

Maine State Nurses Association

Union Mutual
2211 Congress Street
Portland, ME 04102

City of Portland
Special Services Unit

School Nurse, SAD #58

American Red Cross

Maine Hemophilia Treatment Center

Clergy, First Parish Church
Yarmouth

Department of Human Services

Patient Care
Education

Counselling and Testing
Coordinator

Education

Patient Care

Education
Counselling and Testing

Patient Care

Patient Care
Counselling and Testing

Patient Care, Coordinator

Education

Education
Counselling and Testing

Patient Care

Education

Patient Care

CALENDAR

- Oct. 11-12: Mainely Men weekend. Gary Anderson will present three workshops: AIDS 101; Safe Sex; and The Antibody Test.
- Oct. 14: Patient Care Subcommittee meeting at City Hall, Portland, 4th Floor Meeting Room, from 8:30-11:30.
- Oct. 15: AIDS Community Awareness Night at Freeport High School. Time: 7:30 p.m. Contact Dean Patterson, Box 160, Freeport, ME 04032 for more information.
- Oct. 17: "Counseling AIDS/ARC Victims and Concerned Persons" is being presented as part of the 40th Annual New England Conference for Counseling and Development at the Sonesta Hotel in Portland. For more info contact John Sutton at 780-5316 or 829-5005, or Nancy Perry at 829-3887,-3736.
- Oct. 17: A presentation on AIDS will be featured at the annual meeting of the Maine State Nurses Association. Entitled "Mental Health Concerns of AIDS Victims, Family, Lovers, & Friends". Location: In Brunswick at the Atrium Motel Inn and Conference Center, Lincoln Rm. Time: 1:45 - 3:30 p.m. Contact Karen at 622-1057 for more information.
- Oct. 18-19: 2nd Annual Celebrate Our Unity and Diversity Weekend at Hampshire College, Amherst MA, will feature numerous workshops on AIDS. For more information call (413) 774-7998.
- Oct. 18: "Women and AIDS", a day long conference in Boston at Suffolk University, 55 Temple St., Boston, MA. Thirty workshops by women living and working with AIDS will be presented. Contact Jennifer Walters, Fenway Community Health Center, (617) 267-7573. NOTE: This conference is endorsed by The AIDS Project.
- Oct. 25: "AIDS: The Need for Psychological Services" will be presented by Richard Waitzkin, MSW, to the annual meeting of the Maine Psychological Association. Location: USM Campus Center, Portland. Time: 2-3 p.m. Contact Chuck Acker at 622-3751 (ext. 300) for more information.
- Oct. 26: Coalition of AIDS Service Providers meets in Portland from 10-2. Call 236-9593 for more information.
- Oct. 26: "AIDS and How It Affects Us Now", Bates College, Lewiston, 1-4 p.m. Includes an overview of AIDS, HIV antibody testing and a showing of the safer sex film "Chance of a Lifetime". Sponsored by AIDS Action of Central Maine and the Gay Lesbian Straight Coalition at Bates College. Call Al Hurley for more information at 782-6615.
- Nov. 6: Full meeting of the Advisory Committee to the Dept. of Human Services on AIDS. Augusta.
- Nov. 13: "AIDS and Hepatitis B", a symposium at the Augusta Civic Center sponsored by the Division of Disease Control. You must register by Nov. 6. For more info contact Kathleen F. Gensheimer, M.D., State House Station 11, Augusta, ME 04333.
- Nov. 14: "The AIDS Show" on PBS affiliates.

WANTED: A copy of the June '86 (vol #6) issue of CARING, from the National Association of Home Care. To lend or donate your copy, send it to P.O. Box 10723, Portland, ME 04104. We'd appreciate it.

Advisory Committee

page 6

STATISTICS

August

AIDS UPDATE FOR MAINE

As of October 9, 1986:

Number of diagnosed cases: 30

In Southern Maine: 21
In Central Maine: 6
In Northern Maine: 3

Gay/Bisexual: 26
IV substance abuse: 2
Hemophiliac: 1
Transfusion related: 1
Heterosexual contact: 0
Female Prostitute: 0

AIDS LINE 775-1267
1-800-851-AIDS

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